# Next Steps

The Journey Home





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# Introduction

The Irish Neonatal Health Alliance (CHY21984, RCN20100100) is a parent support organisation for families affected by premature birth. The charity was established by families, for families, to help provide the supports and resources that our founding members noted were lacking when they experienced a premature birth.

Once home, you and your family will be the primary carers for your baby. Bringing your child home is an emotional and sometimes stressful time for families, however it is important to remember that your baby is only coming home because the hospital staff believe that they are well enough to leave the hospital and that you are able to care for them.

This booklet has been developed by the INHA to help you prepare to take your baby home from hospital. It does not include information specific to *your* baby's management - it is intended to complement the advice you receive from the staff caring for your baby in the Neonatal Intensive Care Unit or Special Care Baby Unit. We have tried to include as much general information as possible about what to expect and to look out for when you take your baby home but if you have any specific concerns about your child you should contact your General Practitioner, Public Health Nurse or Paediatrician.

Our website **www.inha.ie** has extensive information on a variety of topics connected to prematurity and we would encourage you to visit often to keep up to date with news of research, policy, legislation and support.

#### Irish Neonatal Health Alliance



# **Getting Ready**

#### THE RIGHT TIME TO GO HOME

To help decide if your baby is ready to go home, the caregiving team look at a number of factors including whether your baby is able to maintain their body temperature and how well they are feeding and maintaining weight.

If your baby requires ongoing help or support due to breathing difficulties the team will check to see if this can be managed at home. If your baby is going home with equipment to support their breathing or feeding, you will be given information and training to manage the equipment confidently at home.

#### PREPARING TO GO HOME

We recommend that you start preparing for home as soon as your baby's medical condition has stabilised. It is important to raise any concerns or practical difficulties that you anticipate with your baby's medical team before you go home.

In addition to getting to know your baby it is important that you are confident caring for your baby:-

- 1 Do you know how to make your baby comfortable and supported?
- 2 Have you had the opportunity to bath your baby? Are you happy to do it without help?
- 3 Are you confident administering your baby's medications?
- 4 Are you confident using the specialist equipment that you are taking home with you?
- 5 If you are expressing or bottle feeding, do you know how to sterilise bottles and make up your baby's feed?
- 6 Have you been shown basic CPR skills should your baby stop breathing?
- 7 Do you know how to check and manage your baby's temperature?
- 8 Are you familiar with the techniques to prevent cot death and Sudden Infant Death Syndrome (SIDS)?
- 9 Do you have adequate information and support to continue breastfeeding your baby?
- 10 Do you know who to contact or see if your baby gets sick at home?
- 11 Do you have all of the details and information to attend follow-up out-patient appointments?

Prior to discharge your baby's follow-up appointments will be arranged and documented in your baby's discharge information. The frequency of follow-up appointments will depend on your baby's condition and may change over time.

Many units have designated nursing staff who are responsible for the Discharge Planning Process. If you are unsure about **ANY** aspect of your baby's care - please speak to the Discharge Nurse in your unit. If your unit does not have a designated Discharge Nurse please speak with your child's Neonatologist or Paediatrician.

#### **GETTING READY**

If you plan to express or bottle feed at home with a different bottle/teat to that which is used in the hospital, it is helpful if you bring this equipment into the hospital prior to discharge so that your baby can start getting used to using them before they go home.

You may also like to bring a blanket or cot sheet from home so that once your baby is home from hospital, they will be comforted by familiar objects and smells.

#### TRANSPORTING YOUR BABY HOME: CAR SAFETY

- By law, all babies and children under 150cm in height or weighing less than 36kgs must use a child restraining system suitable for their height and weight when travelling in a car.
- Children weighing up to 13kgs must be carried in a rearward facing car seat.
- The car seat must be appropriate for the child's age and size. Refer to www.rsa.ie for detailed information.
- The seat should be assessed by your baby's medical team to ensure that your baby is stable for travel home.
- The car seat must be installed correctly.
- Ensure that your baby is properly secured in the car seat by adjusting the shoulder straps so that they come from above the shoulder and are not twisted. The harness should fit snugly such that your baby is not able to move his or her arms from under the harness but you can put your finger between the baby and the straps.
- The baby should be supervised at all times when being transported in a car seat.
   Never leave your baby unattended in a car.



#### THE HOME ENVIRONMENT

To prevent the spread of illness (coughs/colds/infection) to your baby, it is important to keep your home safe and comfortable for you and your baby.

- In the first few weeks, it is recommended to limit contact with visitors in your home.
- Monitor the temperature in your home (16°-20° C).
- Keep your baby away from open windows, draughts, fans, heaters and fireplaces.
- Do not overdress your baby as they can overheat.
- Ensure your baby is in a smoke free environment.
- Ensure window blinds and curtains are free of dangling adjustment rods or chains.
- Ensure dangerous medicines and chemicals are stored safely and out of your baby's reach.

#### **SIBLINGS**

During your stay in the NICU and when you come home you will be spending a lot of time with your baby. If you have other children it can be difficult for them to understand why you have not been around and cannot provide them with the same level of attention.

The best way to help them understand is to explain why the baby requires your attention and to explain that over time it is likely this will change. They will also feel better if you find ways to include them which make them feel important. Help them become actively involved in the care of the baby ie preparing for nappy changes or bathing.



# Communicating with your Baby

It takes time to get to know our baby's individual signals and to recognise what your baby is trying to tell you. By responding to your baby's messages, you will be better able to provide what they need.

#### What is my baby trying to tell me?

When your baby is:

Alert	They may be telling you they are ready to play by:  Looking at you Smiling Being bright eyed
Stressed or unable to cope with more stimulation	They may:  Look away Grimace or frown Yawn Cry
Tired	They may:  Have jerky movements  Yawn  Cry  Rub their eyes  Pull at their hair or ears

#### HOW CAN I HELP MY BABY LEARN TO COMMUNICATE?

- Make eye contact.
- Give big smiles and provide encouragement.
- Talk or sing about what you are doing and copy the sounds and face movements your baby makes so they learn to 'talk' to you.
- Give your baby lots of time to respond.
- Give your baby a break if they look tired or stressed.
- Try to avoid having too many distractions around.
- Start reading books from around three months of age.



# Feeding

Before your baby leaves the hospital they should have a feeding plan in place. Many Irish units have specialised staff who will help you with this plan including the lactation specialist, dietician, speech and language therapist and nursing staff. Their goal is to ensure that you are as comfortable and confident as possible with feeding your baby before you go home.

#### THINGS TO REMEMBER:

- Some babies may go home fully demand feeding (which means they wake on their own and give signs that they are ready for a feed).
- Other babies may be recovering from illness or surgery and may need to be woken for feeds at certain times of the day and night.
- If you are advised to feed your baby at set times, it is important to follow this to
  ensure that they are getting all the nutrients and fluids that they need to help
  them grown.
- As you baby grows, you may need to increase the amount you offer your baby at a feed. If you are unsure about increasing your baby's feed amount, or if your baby has special needs, it is advisable to check with your paediatrician, public health nurse or general practitioner.
- Many babies will show signs of wanting more feed by not settling well after
  finishing their usual feed amount or, if fully breastfeeding, they may feed more
  frequently. If this occurs consider offering longer feeding time or offering both
  breasts if breastfeeding and increasing the volume of feed if bottle feeding.
- If you have recently increased the amount of feed you are offering your baby and they are vomiting after feeds try reducing the amount of feed back to the previous amount to see if it makes a difference. Consider increasing the amount again when they are showing you they want more feed.
- Breastmilk is based upon supply and demand to increase your milk supply you need to feed or express more regularly.

Your baby may go home fully breastfeeding or could be using a combination of feeding methods such as bottle and/or tube feeding. Regardless of which method you use it is important to follow certain steps to ensure that feeding is safe and works well for your baby.



#### BREASTFFFDING

If your baby is fully breastfeeding on demand offer your baby the breast each time they show signs of being hungry. Some of these signs include:

- Smacking or licking of lips.
- Fluttering of eyelids.
- Opening and closing of the mouth.
- Moving the arms, hands and lower limbs.
- Moving hands towards their mouth.
- Moving head towards the breast and opening mouth when held close to mother's chest.

It is normal for a well-baby to demand to breastfeed as much as 8-12 times a day or every 2-3 hours.

- Be patient and give your baby time to latch onto the breast.
- If you baby is used to sucking a dummy or takes some feeds from a bottle then latching onto the soft shape of a breast can be more difficult for them in the earlier days.
- A well baby will normally feed for an average of 15-20 minutes per breast.
- Offering one breast per feed, or both breasts, depends on the amount of milk produced in each breast.
- Some mothers may only need to offer one breast at a feed time whereas others may need to offer both.
- If your baby is feeding from combined methods, always offer the breast first so
  that your baby becomes most familiar with this for satisfying their hunger.
- Your baby suckling at your breast will increase your milk supply more effectively than a pump alone.



# WHAT DO I DO IF MY BABY IS SLEEPY AND DOES NOT FEED WELL AT THE BREAST?

- If your baby is awake around the time their feed is due and is in a calm state
  offer the breast first. Avoid other activities which may tire your baby and waste
  energy for feeding including nappy changes, bathing, or excessive crying.
- If your baby becomes sleepy after a short period of sucking at the breast consider a nappy change to help wake them up so you can continue feeding.
- Avoid over dressing or wrapping your baby as this can make them sleepy.
- If your baby remains sleepy despite efforts to wake them you may need to wait 10-30 minutes and try again.
- Some babies discharged home may have ongoing health problems. This may
  mean they do not have enough energy to be able to fully feed each time.
   For these babies your will need to give the remaining feed with expressed
  breastmilk or formula. This is called supplemental feeding.
- Supplemental feeding will need to continue until your baby is feeding from the breast for longer periods and is gaining weight adequately.
- If your baby does not feed long enough to empty the breast you must finish emptying the breast yourself by expressing to maintain milk supply and help avoid mastitis.

A sudden decrease of feeding in a small infant can be a sign that your baby is unwell. If you have any concerns please contact your general practitioner as soon as possible.

#### HOW DO I KNOW IF MY BABY IS GETTING ENOUGH MILK?

#### Weight gain:

Your baby should be weighed at least once a week in the first few weeks after discharge to check how they are growing. This is one of the main signs that feeding your baby is going well. Your Public Health Nurse or General Practitioner can attend to this.

#### Nappies:

- Initially your baby should have six good wet nappies a day.
- Bowel motions can be as often as every feed or 2-4 times a day.
- With a breastfed baby bowel motions are usually yellow and soft .
- The addition of extra calories or formula supplements with breastmilk-fed babies will change bowel regularity and colour.

#### Baby behaviour:

- Your baby should be settled for a period between one feed and the next.
   This will change as baby grows and has more awake periods.
- If fully demand-breastfeeding, your baby may suddenly start feeding more frequently if they have a 'growth spurt'.

#### **EXPRESSING AND STORAGE OF BREASTMILK**

- If your baby cannot fully breastfeed it is important that you express regularly to maintain an adequate milk supply.
- We recommend that you express every three hours for 15/20 minutes each breast.
- If your baby is able to take some smaller breastfeeds, after they have fed express to empty your breast or until they are softer or more comfortable.
- It is important to remember that your breasts produce milk to replace what is taken at each feed. The more you empty the breast the more milk you will produce.
- Using breast massage while pumping can help empty the breast.

#### **BREAST MILK STORAGE INFORMATION**

 For the latest guidelines on storing breast milk, please consult the following website:

https://www2.hse.ie/wellbeing/child-health/expressing-breast-milk/storing-expressed-breast-milk.html

#### HOW DO I WARM BREASTMILK FOR FEEDING?

- Place the container of breastmilk into a bowl or jug of warm water to bring it to room temperature.
- Never microwave or boil milk as it will destroy some of the nutrients in the milk.
- Make sure the milk is not too hot before offering it to your baby.
- If there is any milk left following the feed, do not keep for longer than one hour.
- To check if the water is warm enough and not too hot, dip a finger in the water to test its temperature.



#### **BOTTLE FEEDING**

For some babies and mothers full breastfeeding is not achievable. This can be upsetting and disappointing for mothers who had intended to breastfeed their baby. However, some mothers are able to bottle-feed their baby expressed breast milk or supplement breastfeeding with bottled formula feeds.

Useful information can be found on:

https://www2.hse.ie/babies-and-toddlers/feeding/

#### Helpful hints for bottle feeding:

- Cradle your baby in your arms whilst feeding. Do not prop up the bottle as it can cause choking.
- Look at and talk to your baby to bond while feeding.
- Discard any formula or breast milk if not used within one hour after the feed begins.
- In the early months, feed your baby every two to four hours, waking him/her when small if a nap is longer than four to five hours.
- Sterilise bottles, teats and dummies.
- Observe your baby during feeding for dribbling or choking, which may be a sign that you need to change to a different type of teat.

#### How much should my baby take?

- Feed amounts and times vary from day to day. Follow your baby's discharge instructions.
- Focus on the total amount taken over the entire day instead of the amount taken at one feed.
- Follow the recommendations of your paediatrician or General Practitioner, as the amount of feed your baby takes will change as your baby grows.

#### What formula should I use?

- You may be required to use a specific formula, if so this information will be provided to you before discharge.
- Continue with the formula you used in the hospital.
- Your baby may go home with calorie supplements added to their feed.
   You should continue to give these at home. Request a demonstration from your baby's medical team to show you how to prepare the formula and calorie supplements before discharge.

# How should I prepare the formula?

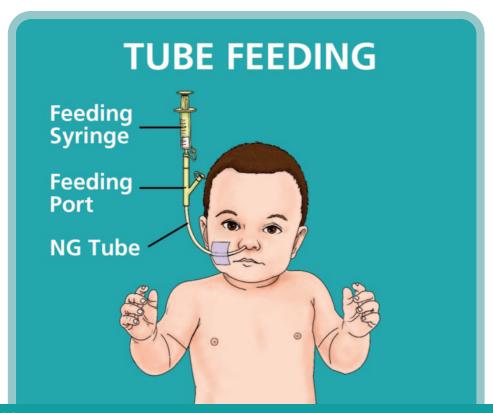
 For the latest guidelines on preparing infant formula, please refer to the Health Service Executive website:

https://www2.hse.ie/babies-and-toddlers/

#### **TUBE FEEDING**

If your baby needs to go home with a tube to either supplement feeds or as the main way of feeding, you will be given demonstrations and education by your baby's medical team to help you do this at home safely. You may feel nervous about using this method at home but your baby will not be discharged home until you are confident with the feeding method.

If you have any concerns about the tube position please attend your nearest Emergency Department for assistance in replacing the tube.



# Settling

#### **BATHING:**

You may feel nervous about bathing your baby but after a while you will get used to managing your slippery baby and your baby will learn to enjoy and may even find bath time relaxing.

#### Safe Bathing Tips

- Babies do not need a bath every day. Some parents will bathe them every day, while others will wash their baby's face, neck, hands and bottom every day and fully bathe them every other day.
- Choose a time for the bath when your baby is awake and content.
- Make sure the room is warm.
- Fill the bath with cold water then hot water, ensuring the water temperature is warm, not hot.
- Check the temperature with your wrist or elbow and mix the bath water well so that there are no hot patches.
- Plain water is best for your baby's skin and you only need to wash your baby's hair two or three times per week.
- If your baby appears scared, try wrapping them in a cloth and gently place them in the bath.
- Always gently support your baby with your hands so that they feel secure.
- Allow your baby to bring their hands together, kick their legs or push their feet off the end of the bath.
- Introduce tummy time in the bath ensuring that your baby's head is supported at all times.
- Bath time is a good way for your baby to wind down, relax and be ready for bed and sleep.
- Babies and children should never be left unattended in the bath.

#### **SETTLING YOUR BABY TO SLEEP**

Sleep is very important to help your baby's brain develop and grow. In the first few months after going home from hospital babies usually sleep about 16 to 20 hours every day and some sleep even longer! However after spending time in the NICU, it may take some weeks to settle your baby into a good sleep routine.

#### Tips on developing a regular awake and sleep time

- Encourage play and stimulation during the day rather than at night.
- Have an evening routine such as a bath, followed by a feed and a story or lullaby in a darkened room.
- Provide a night light or play soft music as babies who have spent time in hospital often become used to low background noise and light for comfort.
- Wrap your baby in a thin cloth such as muslin, with their arms and legs 'bent up' and their hands together.

#### SAFE SLEEPING

It is recommended that healthy babies sleep on their back at night and naptime to decrease the incidence of Sudden Infant Death Syndrome (SIDS). If possible turn your baby's head to a different side with each nap.

# **Safe Sleeping Tips**

- 1 Sleep baby on his/her back.
- 2 Keep baby's head and face uncovered:
  - feet to the bottom of the cot
  - blankets tucked in firmly OR
  - use a safe baby sleeping bag with fitted neck and armholes and no hood.
- 3 Keep baby's environment smoke free before and after birth.
- 4 Keep a safe sleeping environment day and night:
  - safe cot: CEN compliant
  - safe mattress: firm, clean, flat, correct size to fit the cot.
  - safe bedding: soft surfaces and bulky bedding increase the risk of SIDS.
  - NO soft surfaces or bulky bedding NO pillows, NO cot bumpers
  - NO lambswool, NO soft toys in the bed.
- 5 Sleep baby in a safe cot in their parent's room, next to their bed:
  - the safest place for baby to sleep is in a safe cot next to adult caregiver's bed.
  - co-bedding or sleeping in the same bed as an adult caregiver increases the risk of SIDS.
- 6 Breastfeed baby if you can.

#### SLINGS AND CARRIERS.

Consult your Paediatrician if you are considering using a sling for your premature baby.

#### TICKS Checklist When Using A Sling

Т	Tight	Slings should be tight enough to hug your baby close to you.
1	In view at all times	You should always be able to see your baby's face by simply glancing down.
С	Close enough to kiss	By tipping your head forward you should be able to kiss your baby on the head.
K	Keep chin off chest	A baby should never be curled so that their chin is forced onto their chest as this can restrict breathing.
S	Supported back	The baby's back should be supported in a natural position so their tummy and chest are against you.

# Play and Development

Quiet interaction and sleep are important for your baby's development during their first few months. When awake, play is the way that babies learn about themselves and the world around them.

When your baby is born their body responds automatically to certain movements and positions. As they grow and gain more control over both their head and body these reflexes disappear.

#### Tips to help your baby develop control

- Stroke them and draw attention to their body parts as you wash, dry, massage, dress and change them.
- Talk to them as you change their position. Move them slowly so they keep control and have a chance to respond.
- Place them in different positions and encourage them to look at and reach out for things. At first they will be more interested in your facial expressions than toys.
- Help them to see and suck their fingers.

If your baby finds it hard to bring their hands forward where they can explore them:

- Place them on their side to play.
- Round their shoulders forward as you cuddle them.

Babies are trying to make sense of what they are seeing, hearing, tasting, smelling and feeling. You can help them in the following ways:

- Limit how much stimulation they are having at one time. For example, allow them to look away from you and close their eyes when feeding.
- Make use of the short time they are fully awake and alert by interacting with them without distractions for example, turn off the TV or radio.
- Watch out for signs that show you your baby is tired and needs settling, like grizzling, crying, fist clenching, eye rubbing or yawning.
- Even if they appear to like it, do not put your baby in front of the TV or electronic toys. The noise and flashing lights can over-stimulate them and make it hard for them to settle.



#### **TOYS**

There are many toys available for your baby. As they grow their play changes.

#### During their first few weeks:

#### **Mobiles**

Mobiles and things to look at will interest them.

- Mobiles with high-contrast colours and patterns, for example black and white.
- Many babies like mobiles that play music.
- For safety, keep the mobile out of your baby's reach when in bed.

#### **Books**

Reading aloud to your baby each day helps the development of their speech and language when they are older.

- This can be started either in hospital or as soon as you go home.
- Start by naming pictures and using single words and then building up gradually to reading longer stories.
- Soft books or board books with easy-to-see patterns or pictures are recommended.

#### Toys to practise holding

Thin, lightweight toys are best for learning to grasp and hold. Attach some toys to the pram within easy reach to promote play and grasping.

#### Floor play at home

Once you are home, floor play is the most important thing to develop the strength that will be needed for standing and walking.

- Give your baby opportunities to play on their side and tummy as well as on their back. Offer toys and encourage reaching in these positions. Play mats with hanging toys are useful for this.
- Help your baby to find their feet whilst lying on their back by gently bringing their legs and feet towards their hands.
- A mirror (unbreakable) can be used during tummy time.

#### **Supported sitting for play**

Provide opportunities for your baby to play in a sitting position. Offer toys to encourage them to reach and grasp.

From about three months of age, don't forget to sit the back of the pram up so your baby can see what is happening around them.

# Baby walkers and jolly jumpers

Baby walkers encourage babies to walk and spring off their toes while supported in a frame. This does not allow for the natural development of body control, balance and the strength needed for crawling, sitting and independent walking which babies learn when placed on the floor to play.

Baby walkers may delay the onset of walking and encourage tiptoe walking.

#### **TUMMY TIME**

When your baby is born they will spend a lot of time on their back. Place your baby in different positions to help develop their muscles.

- Lying on their tummy will help them develop the neck, shoulder and back muscle strength they need to control their head, learn to reach out, roll and move around.
- Tummy time also helps prevent the back of your baby's head from flattening.

#### What happens when my baby is on their tummy?

When your baby is born they have reflexes that control their arms and legs when they are in different positions. When placed on their tummies, babies automatically turn their head to the side so that they can breathe, and their limbs are tucked close to their body. Having their arms tucked under their chest helps them to balance and lift their head.

# When should my baby have tummy time?

- During the first few weeks when sleeping and eating are high priorities for your baby, one to two minutes on their tummy is enough.
- Babies prefer short frequent periods on their tummy rather than a long time where they may get upset.
- Being physically active, even for a short time, may help them sleep better.
- As they grow older they will be awake for longer and have more time to lie on their tummy to play; they will also like being on their tummy more.

# What if my baby doesn't like tummy time?

- Check they are not hungry or tired.
- Try laying them on your chest. Your baby will enjoy being close to you.
- Lie in front of them so that they can see your face, or place an interesting toy or unbreakable mirror in front of them.
- Get your older children to help distract them.
- Place their shoulders and arms over a rolled towel to make it easier for them to lift their head.
- Offer short frequent periods of tummy time of one to two minutes rather than one long session.



#### When should I seek help?

Seek help if your baby:

- Is a poor feeder and feeds normally take a long time, for example longer than 30 minutes.
- Remains floppy after 1-2 months.
- Feels stiff in their arms or legs or arches their back frequently.
- Prefers their head turned to one side or if you have concerns about their head shape.
- Is not holding their head in the middle or bringing their hands together by three months corrected age\*
- Moves one side of their body more than the other.
- \*Corrected or adjusted age is a premature baby's chronological age minus the number of weeks or months they were born early. For example, a one year old who was born 3 months early would have a corrected age of nine months.

#### Your baby's head shape:

As your baby's head control develops, they should be able to turn their head to both sides. It is a good idea to regularly check the shape of the back of your baby's head.

If you notice:

- an obvious flat spot on one side of the back of the head
- your baby has a strong preference for turning their head to one side
- your baby has difficulty turning their head

please consult your General Practitioner or Paediatrician who may arrange a physiotherapy assessment. This condition is often easily treated with stretches and exercises.

#### Remember:

Developmental milestones are a guide only.

If your baby has not reached these milestones or if you have concerns, discuss them with your General Practitioner, Public Health Nurse or Paediatrician.



#### **DEVELOPMENTAL MILESTONES**

# What should my baby be doing?

Milestones are the stages and skills that your baby reaches as they grow and develop. Sometimes your baby may not be reaching the milestones, especially if they have ongoing medical issues such as needing oxygen or being tube fed. Even babies born at full term will reach their milestones at different ages. If your baby was premature, milestones are based on their corrected age.

AGE WHAT TO LOOK FOR		
1 to 2 months	<ul> <li>Starts to communicate with you by smiling, 'talking' (gurgling sounds) and watching your face very closely.</li> <li>Starts to hold their head for longer when you hold them upright.</li> <li>May prefer to look one way but should be able to turn their head equally to the right and left, beginning to look at toys, but may still prefer your face.</li> </ul>	
3 to 4 months	<ul> <li>Starts to laugh and follow objects and people with their eyes.</li> <li>Shows excitement when something is about to happen.</li> <li>Enjoys babbling and making noises and 'talking' when you talk to them.</li> <li>Is able to push up with their arms, while lying on their tummy on the floor.</li> <li>Has a steady head when held upright and will turn to look in all directions.</li> <li>Brings their hands together and does not favour one hand more than the other.</li> <li>Will grasp a rattle placed in their hand and will swipe at objects to try and grab them.</li> <li>Brings feet together and pulls their legs up.</li> </ul>	
6 months of age	<ul> <li>Starts to enjoy playing peek-a-boo.</li> <li>Loves laughing, squealing and babbling.</li> <li>Sits for a few seconds leaning forward on their hands.</li> <li>Rolls from their tummy to the back and rolls from the back to tummy.</li> <li>Reaches out easily for toys with either hand and moves objects from one hand to the other.</li> <li>Tends to put everything in their mouth.</li> <li>When held takes weight through their legs with heels down and bounces up and down.</li> </ul>	

# Medications

Some babies will require medication after they have been discharged from the hospital. You will be given demonstrations, information and time to practice giving your baby's medications before you go home.

Here are some ways to give medicine to a baby. If one method does not work, try another.

#### Method 1

- Draw up the correct amount of medicine into a syringe.
- Let your baby suck the medicine out of the syringe.
- Give the medicine right before feeding the baby unless your doctor tells you
  not to. This way the baby is hungry and more likely to swallow the medicine.
- When giving medicine to a baby, use their natural reflexes (such as sucking) whenever possible.

#### Method 2

- Stroke their cheek gently. This will usually get them to open their mouth.
   When they open their mouth, put a small amount of medicine on either side of their tongue. Let them swallow, then repeat the process until the dose of medicine is gone.
- Avoid mixing medicine with foods or milk your baby must have as they may begin to dislike the food they need.

#### **Drawing up medications**

Syringes are used for giving liquid medications to children and babies because they measure small doses of liquids more accurately. They come in different sizes, so check the measurement markings on the syringe to make sure it can measure the correct dose.

- 1 Shake the bottle, if necessary, and put it on a hard surface.
- 2 Insert the syringe into the bottle.
- 3 Draw up the liquid by pulling the plunger upwards, until the bottom of the rubber stopper (not the top) reaches the required mark.
- 4 Check that you have the correct amount by holding the syringe upside down at eye level. Ensure there are no air bubbles before giving it to the child.
- 5 Place the syringe into the side of your baby's cheek and gently squirt the plungers with small amount of the medication until all the liquid has been given.



#### If you forget to give a dose (for most medications):

- If you forget to give a dose of the medicine, give it as soon as you remember.
   If it is almost time for the next dose, do not give the missed dose at all and do not double the next dose. Instead give the next dose at the normal time.
- Call your General Practitioner or Pharmacist before giving a missed dose if you have any questions.

#### If a dose is vomited (for most medicines):

- If your baby gags or chokes and spits out the dose before swallowing it, let the baby calm down and then give the doses again.
- If the dose is vomited (thrown up), check with your General Practitioner or Pharmacist before repeating the dose.

#### Storage of medicines:

- Store all medicines out of sight and out of reach of children.
- Light and moisture make many medicines less effective. Keep the container tightly capped and store in a dark, dry place.
- Some medicines need to be kept in the refrigerator. Keep medicines on a shelf
  in the fridge above the reach of children and if possible place in a container to
  avoid contact between medicines and food.
- Always keep medicine in the labelled container it came in.
- If your childcare provider needs to give the medicine, you may need to have a separate supply of the medicine especially for use at the childcare facility.
   Ensure that your childcare provider is able to read the name of the medicine on the container and the directions.
- If you need to carry medicines with you, ensure they are kept secure and out of reach of children at all times.
- Do not use any medicine after the expiration date printed on the container.
   Some medicines may have an expiry date based on how long the medication container is opened, particularly oral liquids or syrups. Check with your Pharmacist if the medicine is new or different to what you have had previously.
- If your doctor decides the medicine is no longer needed, you should return the
  unused medicine to a pharmacy for safe disposal. Do not store medicines you no
  longer use or give it to anyone else to use.
- Remind visitors in your home to keep their medicines out of the reach of children.



#### Keep a record

Each time you give a medicine to your baby, keep a record of the time and amount of medicine given. This will help you to keep track of the amount given and help make sure the maximum daily dose is not exceeded. Take this information with you when visiting any health professionals.

The important information to record includes:

- Date and time given.
- The medicine's brand name.
- Medicine's strength.
- Exact amount given.
- Why the medicine was given.
- Who the medicine was given by.
- The daily total amount.

When more than one person is caring for a baby, it is easy for the baby to be given too many or not enough doses of medicine. Keeping a written record will help prevent mistakes. Make sure that every care has clear written instructions about when and how much medicine to give the baby.

#### Safety tips for giving medication to infants (newborn to one year old)

- Do not squirt medicine directly at the back of the baby's throat. This may cause them to choke.
- Let the baby swallow all the medicine before you give more.
- Bring all your child's medicines with you (in the original containers) whenever your child sees a doctor, goes to the emergency department, or is admitted to hospital. This helps the doctors take care of your child.
- If the medicine looks different than usual, ask the Pharmacist if it is the right medicine before giving it to your baby.
- If your baby takes too much of the medicine, or if someone else takes the medicine, call the National Poisons Information Centre on 01 8092566. They will tell you what to do.
- The doctor has prescribed the medicine for your baby only. Do not give it to anyone else.

# **IMMUNISATIONS (VACCINATIONS)**

Immunisation protects not only children but the entire community from a number of potentially life threatening but preventable diseases.

The Immunisation Schedule is designed to encourage administration as early and as safely as possible, offering maximum protection, particularly for infants. It is important that each vaccination is given on time. The National Immunisation Office website <a href="http://www.hse.ie/eng/health/immunisation/">http://www.hse.ie/eng/health/immunisation/</a> provides all the necessary information relating to the immunisation program in Ireland.



#### REDUCING THE RISK OF INFECTION

Babies rely on protection against some infections and illnesses which they receive from their mother prior to birth and some ongoing protection they receive from breastfeeding. The development of their own immune system takes place over a number of months which means they are more at risk from infection when young. There are a number of steps you can take to help reduce the risk of infection. Hand washing is the best way to prevent illness.

- Keep antibacterial soap, paper towels and liquid hand sanitizer handy.
- Wash hands frequently throughout the day, always before feeding your baby and after every nappy change.
- Ask friends and family to wash their hands before touching your baby.
- Keep waterless soap (alcohol hand gel) in your car and nappy bag.
- Wash your baby's toys and dummies regularly in hot soapy water.

# To wash your hands well you must:

- Have paper towel or clean towel handy.
- Wet hands with warm water, then add soap.
- Rub hands together and lather. Wash hands for 20 seconds.
- Wash around fingernails and between fingers.
- Rinse with warm, running water.
- Dry hands completely with paper towels or clean towel.
- Turn off the tap with the towel.

#### To further reduce the risk of infection when your baby is young:

- Avoid places where there are large groups of children.
- Avoid crowded public places.
- Avoid large air-conditioned buildings such as shopping centres and cinemas.
- Ensure everyone coming into contact with your baby washes their hands thoroughly with soap and warm water.
- Reduce contact if someone has a cold, fever or is unwell.
- Encourage adults coming in contact with your baby to have up-to-date immunisations.



#### WHAT IF MY BABY IS SICK?

Call or go see your General Practitioner if you are worried about your baby or they appear sick or start to act differently. Babies can get sick very quickly. Early detection and review by a General Practitioner is always better.

Other than a high or low temperature, watch for the following signs of illness:

- Are they vomiting? Is it more than usual? Has the colour changed?
- Do they have frequent watery stools? Has their stool pattern changed?
- Are they having fewer than six to eight wet nappies a day?
- Is there a change in their skin colour? Are they paler than usual? Are they blue or mottled?
- Are they breathing quickly, is it noisy or are they having pauses in their breathing?
- Are they not interested in food or reluctant to feed?
- Are they less aware of you, not waking up as easily, or floppy?
- Are they less active than usual and more unsettled or irritable?
- Do they have blotchy skin or a rash that doesn't disappear when a glass is pressed against it?

If there are any or a combination of these signs and symptoms contact your GP.

#### What should I do if my baby has a high or low temperature?

- If your baby is less than three months old, call your baby's doctor right away.
- If your baby's temperature is high, remove some clothing and keep checking their temperature regularly. Make sure they don't get cold and seek medical assistance.
- If your baby is cold, check that they are not wet. Change any wet clothing or nappies, put a hat on them and wrap them. Recheck their temperature and seek medical assistance if the temperature does not improve.
- Try to give your baby a feed.

If you feel that your baby immediately requires help call an ambulance on 999 or 112.

#### **GOING OUT**

Going out with a new baby requires preparation and can sometimes take longer than expected. Be flexible with your expectations of what you can achieve the first few times you go out. Try not to have rigid timelines, adjust your plans based on how you and your baby are feeling and take with you anything that you think you may need.

General suggestions when taking your baby out include:

- Dress the baby according to the weather. Babies can burn easily. Avoid direct sunlight and use sunscreen from six month of age. Dress your baby with protective clothing and a hat.
- Avoid large crowds for a few months after discharge, especially during cold/flu and RSV season.

#### RSV RESPIRATORY SYNCYTIAL VIRUS

Although RSV is the most common cause of respiratory tract infection in children under five years of age, most people are unfamiliar with the disease. RSV can be particularly serious in infants born prematurely, children under the age of two suffering from chronic lung conditions, and young children with haemodynamically significant congenital heart disease. Multiples are also at increased risk for serious RSV disease.

Virtually all children are exposed to the virus during the first two years of life and re-infection throughout life is very common. Infants born at less than 36 weeks gestational age are at a significantly elevated risk for severe RSV disease. For otherwise healthy children, RSV usually amounts to little more than a cold. However, for preemies and other at-risk infants, the health consequences can be much more serious. RSV spreads easily from person to person via respiratory secretions. The chance of spreading the virus within a family is very high. Many times school-aged children have introduced the virus into the family. Despite strict infection control procedures, hospital nursery units, creches and other similar institutions are also at high-risk for RSV outbreaks. To help protect your baby, there are simple steps that parents and caregivers can take:

- Have family members and caregivers wash their hands with warm water and soap before touching the baby
- Avoid being around the baby if you have a cold or fever
- Avoid exposing the baby to other children with cold symptoms
- Keep the baby away from crowded places
- Never smoke around the baby
- Talk to your baby's paediatrician about RSV risks and prevention

# Symptoms of RSV often resemble a cold at the beginning:

- Fever
- Runny nose
- Sniffles



# Signs to watch for as RSV progresses are:

- Persistent coughing
- Difficulty breathing
- Wheezing
- Very rapidly breathing or gasping for air
- Blue lips and area around the mouth and under fingernails
- Fever over 100.4 degrees in an infant under 3-months-old, over 101 degrees in an infant between 3-6 months-old, and more than 103 degrees in an infant over 6-months-old.

The child's condition can worsen VERY quickly. If there is more than one child in the home, RSV can spread rapidly throughout the home. This is one of the major reasons why RSV is such a great concern to multiple birth families. In all likelihood if you have one baby with RSV that means that each of your other babies have most likely been exposed to it as well and could quite possibly have it also. RSV season lasts from October through March. It is very, very easy to contract RSV. It is spread by physical contact (such as shaking hands with an infected person) or by air droplets (caused by an infected person sneezing or coughing). RSV can also live for up to 6 hours on surfaces, such as doorknobs, telephones, tap handles, counters or used tissues and burp cloths. RSV infections are very common in areas where people are crowded together (either in living together or even taking mass transportation) and in creches. In homes where there are multiple children, RSV can spread very rapidly from child to child. Older brothers and sisters may bring the virus home from school or friends' homes.

It is advisable to apply for a Drugs Payment Scheme Card for your infant prior to discharge home from the NICU in order to assist with the cost of any medications that your infant may require. To learn more about the HSE Drugs Payment Scheme please refer to the following link:

www.hse.ie/eng/services/list/1/schemes/drugspaymentscheme/



# Parent Self-care and Support

Having a baby in the Neonatal Intensive Care Unit can be a stressful, emotional and traumatic time for you. You may have felt feelings of intense sadness, grief, guilt, shame, anger, disbelief and numbness going through this time, especially when your baby reaches milestones or if they suffer set backs. It is normal to have these feelings. Your baby's time in hospital may be one of the most stressful times you will ever experience. Knowing that what you are feeling is common to most NICU parents may give you some comfort or relief and help you to know that you are not alone.

You may find it helpful to have someone outside of your usual support network to provide you with more information about your baby's illness or condition and other services that are available to help you after discharge. If you would like information on these resources please contact the **Irish Neonatal Health Alliance**.

If you are experiencing any distressing symptoms that are causing you concern, speak to your General Practitioner who can provide you with assistance.

You may have developed a range of effective strategies for coping during your baby's admission, however after discharge it is important that you continue to develop strategies to support yourself as you care for your baby at home.

#### Some suggestions to support you include:

- Take it one day at a time.
- Try to maintain some type of normal routine or develop a new one.
- Try to plan for periods of sleep and rest.
- Participate in regular exercise to relieve stress and tension.
- Eat a balanced diet. Limit junk food. Drink plenty of water.
- Take time to be with people who comfort and recharge you.
- Seek or accept help when needed.
- Don't try to do too much, avoid doing non-essential household jobs.
- Create a support system for yourself and your family.



#### POSTNATAL DEPRESSION

When anxiety or depression begins in the year after birth, it is referred to as postnatal anxiety or postnatal depression. Postnatal anxiety and depression can be a frightening and isolating experience as parents try to deal with their health at the same time as needing to care for a new baby. There are treatments, supports and services available to help you through this experience. If symptoms last for more than two weeks, it's time to seek support.

The signs and symptoms of postnatal anxiety and depression can vary and may include:

- Panic attacks (a racing heart, shortness of breath, shaking or feeling physically 'detached' from your surroundings).
- Persistent, generalized worry, often focused on fears for the health or wellbeing of your baby.
- The development of obsessive or compulsive behaviours.
- Increased sensitivity to noise or touch.
- Changes in appetite: under- or over-eating.
- Sleep problems unrelated to the baby's needs.
- Extreme lethargy: a feeling of being physically or emotionally overwhelmed and unable to cope with the demands of chores and looking after baby.
- Memory problems or loss of concentration ('brain fog').
- Loss of confidence and lowered self-esteem.
- Constant sadness or crying.
- Withdrawal from friends and family.
- Fear of being alone with baby.
- Intrusive thoughts of death or harm to yourself or baby.
- Irritability and/or anger.
- Increased alcohol or drug use.
- Loss of interest in sex or previously enjoyed activities.

If you are experiencing any of these symptoms or are concerned about any other area of your health, contact your General Practitioner.



# References

Discharge Planning In the Neonatal Intensive Care Unit, a literature review.

https://www.tcd.ie/library/support/subjects/nursing-midwifery/assets

#### **Road Safety Authority**

http://www.rsa.ie/RSA/Road-Safety/Campaigns/Current-road-safety-campaigns/No-Child-Car-Seat---No-Excuse

www.breastfeeding.ie

www.healthpromotion.ie

 $\label{lem:http://www.hse.ie/eng/health/az/P/Postnatal-depression/Symptoms-of-postnatal-depression. \\ html$ 

http://www.babycentre.co.uk/a1047947/how-to-give-your-baby-medicine

http://www.hse.ie/eng/health/child/childsafety/tummy\_time.html

http://www.cyh.com/HealthTopics/library/Going\_Home\_What\_Next

http://www.hse.ie/eng/health/immunisation







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